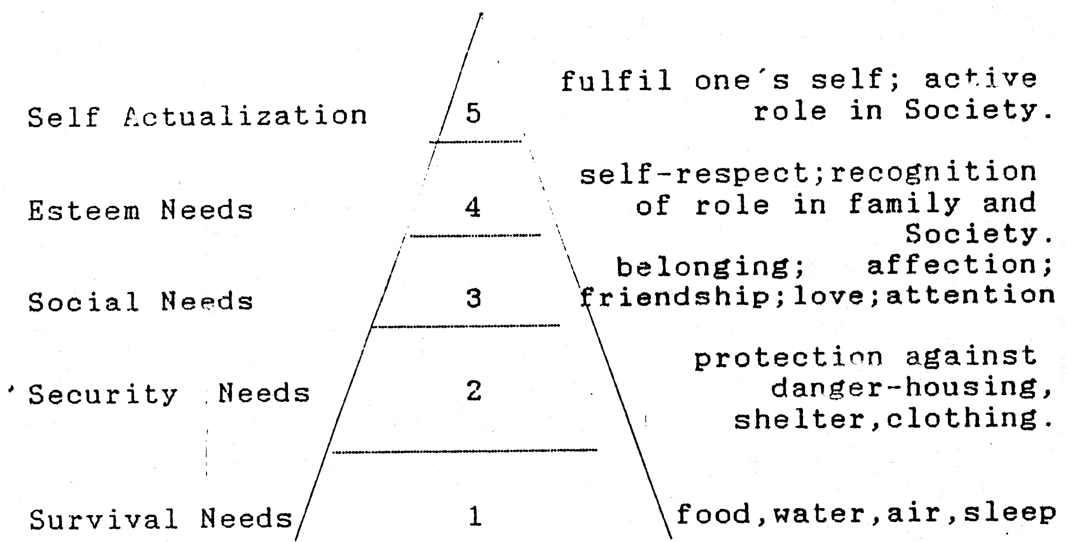
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IV. PRINCIPLES OF REHABILITATION

Refer to the socio-economic situation of people with disabilities. This is what rehabilitation seeks to change. These changes can be illustrated using Maslow's Theory of Motivation and Dajani's Theory of Human Relationships.

1. Basic Human Needs (Maslow, 1908-40)

A reference to Maslow's hierarchy of Basic Human Needs is pertinent.
Maslow described 5 levels of human needs; lower levels to be fulfilled first before higher levels are felt.



Rehabilitation must give people with disability the opportunity of fulfilling these basic needs; of living a fulfilling, and as 'whole" a life as possible; being useful, taking part in adventure and play, in family and in community activities.

Relate these needs to conventional approaches.

Whereas they may provide services to meet very effectively needs of levels 1 & 2, that their activities are directed at the fulfilment of needs at higher levels is questionable.

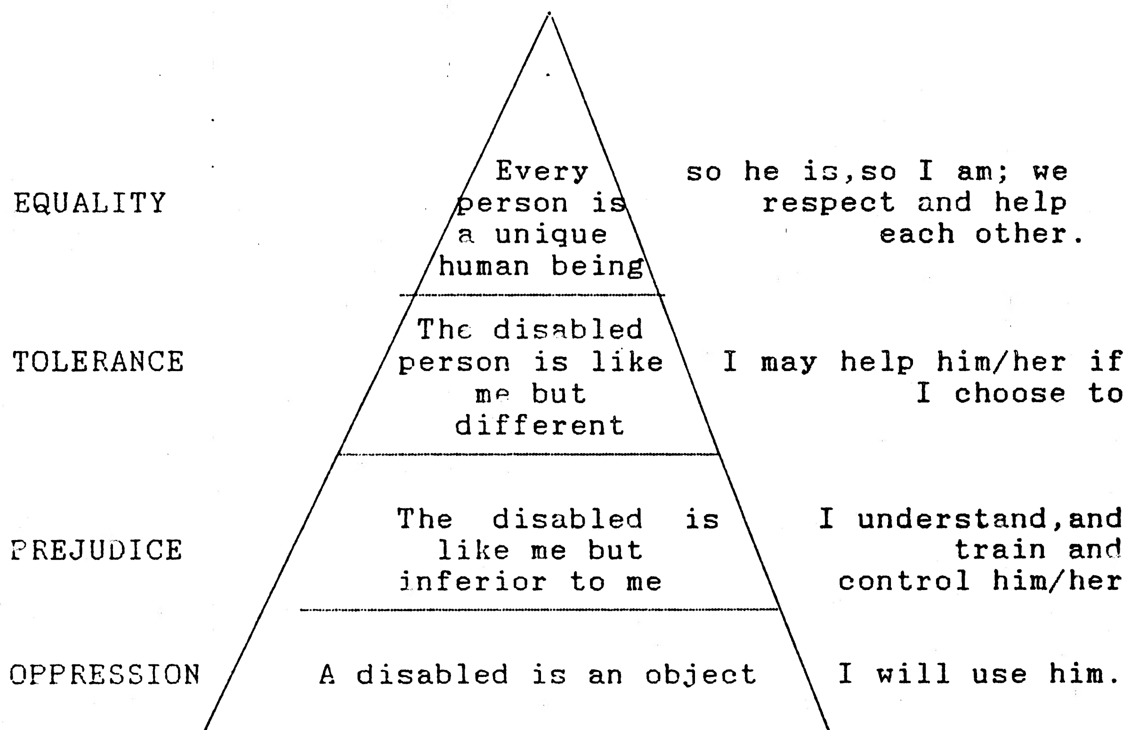
2. The goal - social integration and equality

Do services available at present facilitate the achievement of equality? Or, segregating as they do disabled people as a 'different' group who need separate services, do they emphasize negative attitudes in Society in general?

At this point let's focus on Society's attitudes towards disability and people with disability.

Consider 'Stages in Human Relationships' described by Dajani, and adapt it to the situation of people with disability.

Stages in Human Relationships (Dajani)
adapted to the situation of people with disability



EQUALITY: to accept, respect, feel comfortable with, assist, & welcome into own lives; to appreciate the abilities of, ensure possibilities for, and equal opportunities of, people who have disability

SUMMARY: The principles underlying the CBR strategy is to make available to people with disability services which will enable them to achieve;-

(i) social integration
(ii) equalization of opportunity
(iii) self-realization

3. Application of Principles

Refer to the needs expressed by people with disability, their families and community (Annex I). The needs expressed appear to have 3 main underlying causes;-

- the disability itself
- attitudes of society
- the physical environment

- which contributes most?

Rehabilitation must therefore have 3 aspects;-

- bring about changes in the attitudes of individuals, families, communities and Society as a whole
- provide technology to develop abilities and overcome the consequences of disability.
- improve access and bring about freedom of movement.

To what extent are conventional approaches directed at these aspects?

Hence the redefinition of Rehabilitation in 1981;

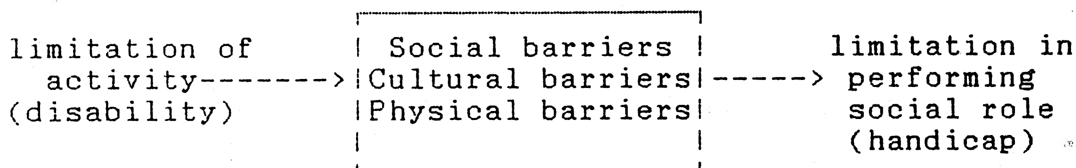
"Rehabilitation includes all measures aimed at reducing the impact of disabling and handicapping conditions, and at enabling the disabled and handicapped to achieve social integration.

Rehabilitation aims not only at training disabled and handicapped persons to adapt to their environment, but also at intervening in their immediate environment and Society as a whole in order to facilitate their social integration. The disabled and handicapped themselves, their families, and the communities they live in should be involved in the planning and implementation of services related to rehabilitation."

Social Integration is defined as "active participation of disabled and handicapped persons in the mainstream of community life."

CONCLUSION

Consider the processes calling for change in rehabilitation in the context of the World Programme of Action;-



CHANGE SOCIETY'S ATTITUDES

The CBR concept envisages a social model for rehabilitation as a change from the conventional medical model. This has been the basis for the development of the WHO Manual 'Training in the Community for People with Disabilities'.

IV. CHANGING PATTERNS IN REHABILITATION DELIVERY

Approaches:

- institution-based rehabilitation
  people with disability come to an institution for the service, and decision-making remains with the institution.

- outreach rehabilitation
  professionals/trained workers from institutions or organizations deliver the service at the periphery.

- community-level rehabilitation
  an extension of outreach, where community workers work under the supervision of professionals/trained workers from institutions or organizations;
  tendency now also to set up small institutions (centres) in the community.

The factor common to all above approaches is that the primary focus of change is the individual who has disability.

- community-based rehabilitation
  rehabilitation is a component of mainstream community and social development;

Often confusion between Outreach/community level and CBR. Some people do Outreach/community level and call it CBR. Difference between 2 need to be stressed in light of the goal the World Programme of Action strives to achieve. (refer Why CBR?)

OUTREACH/COMMUNITY-LEVEL;
responsibility lies with organizations or institutions;
knowledge, and therefore control, is kept by service providers from outside

CBR: primary responsibility lies with community;
knowledge, and therefore control, is made available to people with disability, their families and community.

HENCE THE IMPORTANCE OF THE WHO MANUAL

In CBR there is a move from:

medical model	———>	social model
focus on individual alone	———>	focus also on Society (with greater emphasis here)

There is a current trend to take institutions out into the community and call it CBR.
Others give this new names such as "community-directed", "neighbourhood centres" etc. In some instances people come to the institution for the service, in other instances trained workers visit homes. Is this CBR?

There is also a tendency by a few particular groups to call all services outside the institutional model "community-based rehabilitation".

International NGOs appear to have increasingly more money to spend on rehabilitation in developing countries. There is a danger that patterns that suit them are in many instances being implemented and being called `CBR´.If this trend is allowed to continue it could perpetrate dependence similar to the situation with the institutional rehabilitation approach.

These approaches are of course convenient for service providers. They are easy to implement. But they involve high costs, have low coverage, show a dependence on expatriate personnel, isolate people with disability, are not directed towards integration and equalization.

So how can these approaches be called CBR?

V. WHY CBR?

An analysis of why the concept of CBR evolved provides an introduction to the understanding of it;
Two underlying reasons for the evolution of the concept;-

- o situation of people with disability
- o failure of conventional services to have an impact on that situation.

1.Quality of Rehabilitation

To quote from `The World Programme of Action Concerning Disabled Persons´(WPA) people with disability are `segregated and debased and live on the fringe of Society´.Situation can also be looked at from the consequences of disease.(refer THE DISABILITY PROCESS above).
In terms of changing this situation, consider the adequacy of conventional approaches with regard to quality.
Can an individual in an institution achieve social integration? achieve self-realization?
CBR builds on the most valuable resources developing countries have, each at their present stage of development - the strength of family patterns, community support systems, love and support of family members. and active development proceses and programmes. Individuals continue to live at home like other family members.

2.Accessibility of conventional services to people in need:

(i.e. coverage given by services at present)

Global estimates of disability and handicap

People with disability	5 - 7%
People with handicap i.e.needing services	1 - 2%

Sept. 23 II

INTERNATIONAL COURSE IN COMMUNITY-BASED REHABILITATION

20 September - 29 October 1993

RANDOM NOTES IN DISABILITY CONCEPTS

and

REHABILITATION PROGRAMME DEVELOPMENT

Padmani Mendis

Types of services needed	% of population	
training to diminish the consequences of disability	1.0	
job placement	1.0	
schooling (children & adults)	0.8	
:total with rehab needs	2.0	2.0
people with very severe disability needing care		0.5
care/rehabilitation not needed		3 - 5

Whilst these are global estimates arrived at by WHO, it also estimates that only 1-2% of people with rehab needs have access to services of any kind.

i.e. 98-99% OF PEOPLE WHO NEED REHAB HAVE NO ACCESS TO IT

At the same time, today there are probably about 4000 rehab projects in developing countries. And at least USD 300 million is available annually for service provision, made available by Governments and international NGOs. Coverage afforded by present services is limited by unnecessarily high costs due to lack of cooperation and coordination between donors. (EH/WHO)

3.Distribution of services:

Where services are available they are situated in large cities and other urban areas. Generally over 70% and some times even 90% of populations are rural. These populations have zero coverage.

4.Costs:

CBR does not call for the construction and maintenance of large new buildings. The possibility of using existing infrastructures and maximising the use of existing personnel minimises recurrent costs.

The cost of CBR estimated by WHO is USD 7-10 annually per individual. Compare this with the cost per individual in institutions which ranges upwards from USD 600 annually in the same region.

When a plan for extending rehab using conventional methods in an african country was scrutinized 'it appeared that if the entire health budget for the country was utilized solely for rehab services, they would take 60 years to develop the necessary manpower (11 occupations)and about 200 years to provide the present needy population with the desired amount of care'.(WHO,1976)

Institutions have low turnover and high unit costs;
high capital costs, high recurrent costs.

Who meets these costs?

Donors often meet capital costs and may assist with recurrent costs for a few years;when they withdraw countries find that they cannot meet recurrent costs.Quality and coverage deteriorates.

One must therefore be very cautious when setting up new rehabilitatin institutions. First identify what can be done at community levels, and determine what the support and referral needs are. Use institutions to meet those needs.
For example, some times there is a desire to build expensive and large centralised orthopaedic workshops to make all kinds of mobility aids. But in CBR many technical aids can be made at community level by family members, local carpenters and blacksmiths if they have some instruction (eg WHO Manual) or models. So there is little use for orthopaedic workshops to make crutches and walking frames for community use. They can concentrate instead on making more complicated equipment To make sure they are accessible to communities, smaller decentralised workshops will probably be more useful.

Global Estimates of Costs & Coverage

		1985	2000
total no. in need of services		110 m	150 m
present coverage		2 m	
:gap		108 m	?
CBR costs for one individual	USD	7 - 10	
CBR costs for 110 million	USD	770 - 1 billion	

At present multilateral, bilateral and NGO aid provides a total of USD 300 million for rehab, giving a coverage of 2%.
The gap of 108 million unserved people exists because of lack of cooperation and coordination between UN agencies, between international NGOs, between national NGOs, between governments and NGOs, and between government ministries and departments.

5. Lack of Professionals

Instituition-centred rehabilitation requires large numbers of highly skilled professionals whom we do not have and cannot afford to educate.

We often find in our hospitals that the few skilled professionals we have are performing very simple tasks in rehabilitation. With CBR family members and people with disability perform these simple tasks. Then the skilled professionals have time to do more specialized work.

If we think about it, where are our people with disability today? Very few are in institutions. More than 99% live at home. What CBR does is to provide them, their family and community with the knowledge, skills and attitudes necessary for rehabilitation. This is done within their own socio-cultural ethos,not taking people with disability to a strange environment to be "rehabilitated".

6. Role of Institutions in CBR

provide support to the community level by;-

- providing referral services
- training appropriate manpower
- conducting research studies
- providing short-term institutional care for intensive therapy and to reduce strain on families.
- providing mobile consultants etc

VII. SIGNIFICANCE OF THE CONCEPT

.Implications of word usage;

The term community-based reflects community responsibility for rehabilitation of its members who have disability.

The experience of other development activities has shown that positive attitude change is brought about when people participate actively in the processes calling for change.

Attitudes

Positive Negative

good Unwanted

how are they related?

Behaviour

Does behaviour always reflect attitudes?

Attitudes cannot be influenced from outside - social change cannot be imposed from outside. change must come from within; people need to be aware of the change called for and take responsibility for that change, participating in the processes relating to the change,if it is to be effective and lasting..

THE EMPHASIS THAT SOCIAL CHANGE MUST COME FROM WITHIN THE COMMUNITIES IN WHICH PEOPLE WITH DISABILITY LIVE HAS BEEN ONE OF THE UNDERLYING PRINCIPLES OF CBR.

why?

GOAL
Social integration & Equality

SITUATION
`segregated and debased´
`on the fringe of society´

how to change?

strategies

training for the individual to overcome the consequences of disability

change attitudes of society to bring about equality

CBR

Influence positive attitudes

Services

Freedom of access

Social integration

Equality

Conventional approaches focus on changing the individual alone; CBR involves strategies to also bring a change in Society so that the individual with disability can participate equally.

Consider the evolution of rehabilitation's definitions.

WHO 1969; As applied to disability, this is the combined and coordinated use of medical, social, educational and vocational measures for training or re-training the individual to the highest possible level of functional ability.

WHO 1981; (see above, page 22)

2. Community Responsibility

```
                COMMUNITY                   RESPONSIBILITY
                    |                             |
                    |                             |
   social entity-`intrinsic force'                |
                    |                             |
                    |                             |
   intrinsic social organization                  |
                    |                             |
                    |                             |
           leadership ............................|
                    |                             |
                    |                             |
       group        individuals ..................|
                    |                             |
                    |                             |
                    |                             |
      community development ......................|
                    |                             |
                    |                             |
 ┌──────────────────────────────────────┐ ......|
 |                  |                   |         |
 ├ health       ├ education   economic ┤         |
 ├ sanitation   ├ housing     cultural ┤         |
 ├ sports       ├ transport     social ┤         |
 ├ recreation   ├ access     political ┤         |
 |                  |                   |         |
 |                  |                   |         |
 └──issues  related  to  disability──┘ ......┘
```

When services for people with disability become part of a community's responsibilities towards its own development, then attitudinal change is brought about from within and manifested in behavioural change, which in turn is likely to remove social, cultural and physical barriers. That this happens in CBR is evident in recent quantified evaluations of programmes.

3.Social integration and equality - the goal;

Extracts from the World Programme of Action Concerning Disabled Persons'(WPA);-

`1.The purpose of the WPA is to promote effective measures for prevention of disability, rehabilitation and the realization of the goals of full participation of disabled people in social life and development,and equality. This means opportunities equal to those of the whole population and an equal share in the improvement of living conditions resulting from social and economic development.'

`18.Services for disabled persons should be provided, whenever possible, within existing social, health,and labour structures of society'

It follows that it is only when issues related to disability are considered to be a part of overall community development, that equalization is possible;

When issues related to disability are taken as a community responsibility and as a social development activity, services for people with disability are integrated in other community development activities.Consider areas of need in relation to community development - education, employment creation, housing, health, access, transport, construction etc. Unless a community sees it as their responsibility, no change will come about because it is the community that undertakes these activities.

Moreover, if services for people with disability are not a part of mainstream development effort, where is the integration, the equality?

In CBR equalization is promoted in the following ways;

- educational provision for children with disability is considered within the existing school system with resources and inputs to meet their special needs;
- health services include a system for early detection and for making available to people with needs services to overcome the consequences of their disability; & for prevention of disability.
- housing programmes consider needs of people with disability.
- transportation, design & construction consider access.

- poverty alleviation and social welfare programmes include people with disability when relevant.

- employment creation programmes include people with disability.

- etc etc

Moreover, disability related programme development keeps pace with overall community development, whatever the level of development.

CONCLUSION

Rehabilitation implemented as an isolated issue does not facilitate social integration and equalization of opportunities. Services for people with disability must be part of a community´s mainstream efforts towards its own development.

"America needs to bring the disabled into the mainstream, not relegate whole groups of our people to the backwaters of our economy"
- Senator Edward Kennedy in his address to to the Democratic Convention in 1988.

VII. CBR IN PERSPECTIVE

INSTITUTIONAL REHABILITATION

Individual ———> Institution ———> Home?

REHABILITATION SEGREGATES AND ISOLATES INDIVIDUALS AND EMPHASIZES NEGATIVE ATTITUDES OF SOCIETY

OUTREACH REHABILITATION

Trained Rehab Worker

Individual at home

- Early Stimulation
- Independence in self-care
- Independence in mobility
- Technical aids
- Self-employment

REHABILITATION AS ISOLATED ACTIVITIES DIRECTED AT INDIVIDUALS

CBR

Community Responsibility

for

Rehabilitation as part of Community Development

- Services for individual at home
- Referral services to meet other needs
- Schooling in existing system with special needs being met
- Job training
- Income generation
- Access, housing, transport
- Health, sanitation
- Cultural, social & political activity
- Sports, recreation,
- etc, etc.

REHABILITATION COMPREHENSIVE AND DIRECTED TOWARDS SOCIAL INTEGRATION AND EQUALITY

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VIII. CBR PROGRAMME DEVELOPMENT

In earlier notes reference has constantly been made to CBR, and in doing so, the concept has been described.

To summarize it; the concept envisages-

- bringing about social change towards the acceptance of people with disability as equal and participating members of the community as a necessary pre-requisite for interventions on the individual to be successful.

- social mobilization so that community responsibility for rehabilitation is accepted as part of its overall development

- active participation of people with disability, their families and community in organizing services and interventions to overcome the consequences of disability.

- support of intersectoral referral services at stratified levels.

- use of appropriate technology at each level; i.e.making available to people with disability, their families and community rehabilitation knowledge and skills (information disemination), and selecting technology for middle and higher levels.

The CBR approach developed by the UN agencies with WHO as the lead agency envisages CBR as being a component of PHC.

This approach of CBR can best be described in 4 areas;-

1. Service Structure
2. Technology
3. Manpower
4. Management

RANDOM NOTES IN DISABILITY CONCEPTS & REHABILITATION PROGRAMME DEVELOPMENT

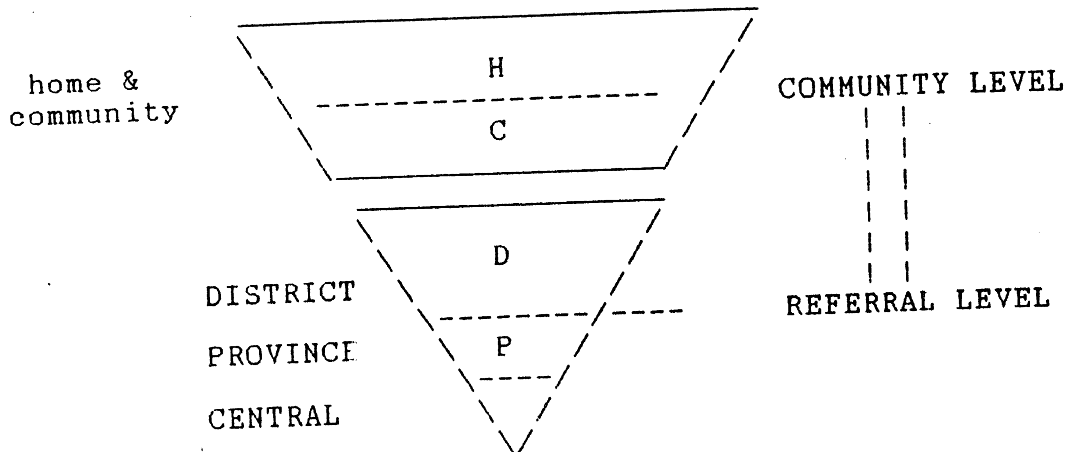
Padmani Mendis

OVERALL CONTENT

IX .CBR Service Structure

refers to the organization of services at different levels so that the needs of the consumer are met, at the same time being cost-effective to the management.

Basically two levels of services;-



Referral services make available interventions which cannot cost-effectively be implemented in the home and community.

Examples of referral needs;
- o diagnosis, medication and surgery
- o specialised rehabilitation therapy
- o auditary assessment and equipment
- o visual assessment and spectacles
- o other specialtechnical aids(tricycles,prostheses etc)
- o higher education
- o specialised vocational training

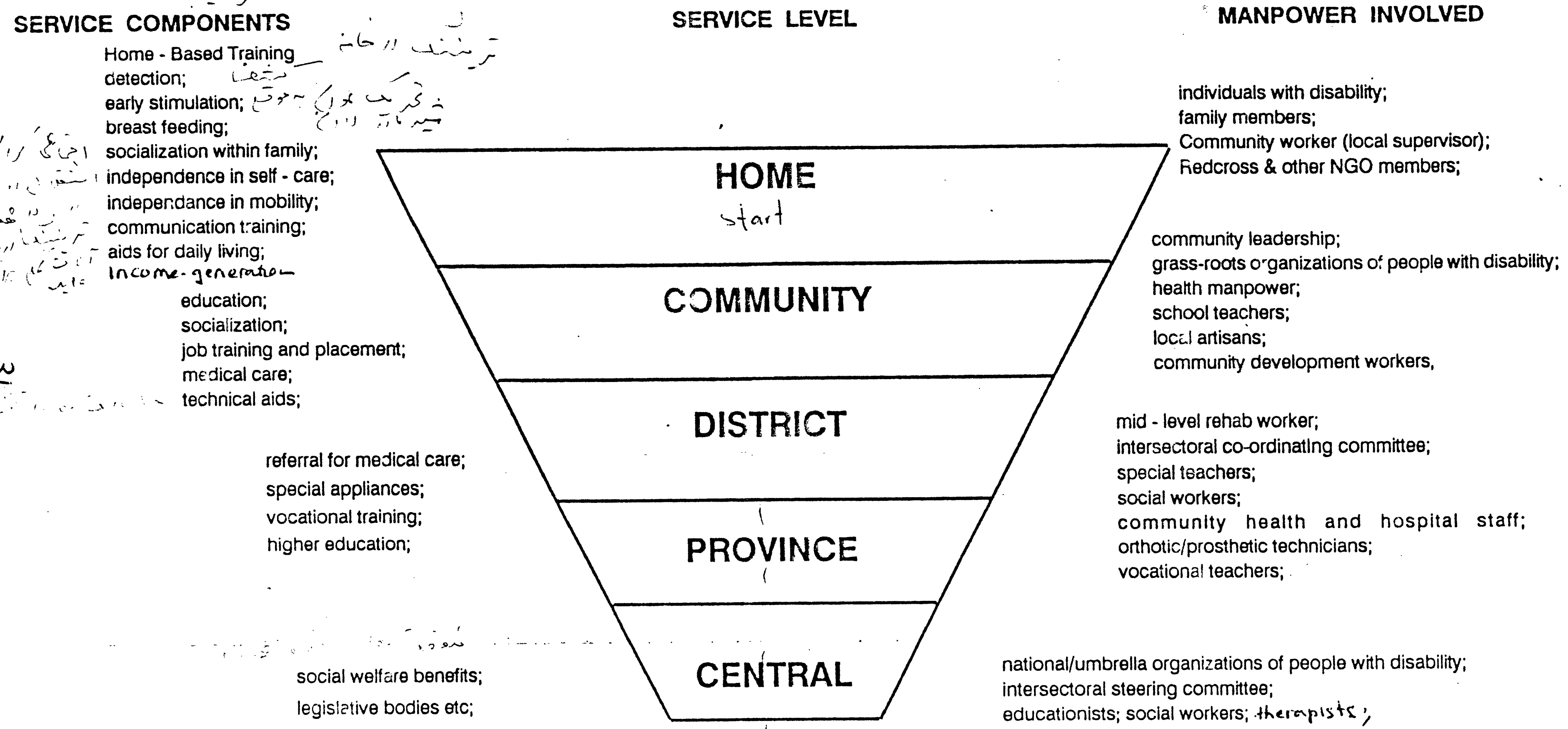
Referral services are made available at successively higher service/adminstrative levels according to their cost and frequency of usage. See ANNEX II.

1.Types of delivery systems

1. single disability
   multiple disability
2. vertical (specialised)
   horizontal (integrated)
3. centralized
   decentralized
4. single level
   multiple level
5. continuous/long-term
   ad-hoc/short-term

بعضی از جنبه (زمینه) های سیستم کمک رسانی CBR

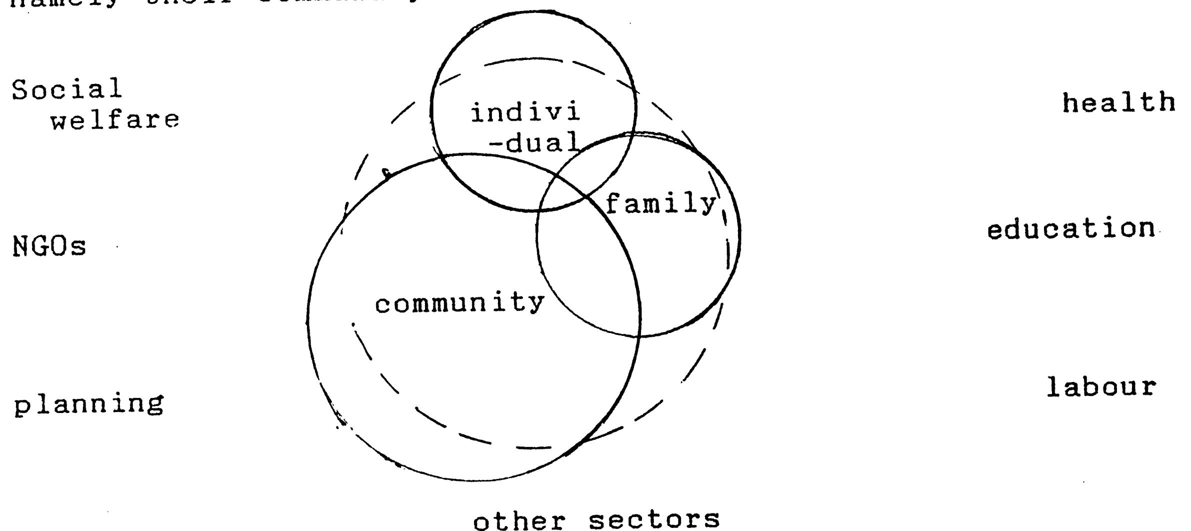
FIG.2 SOME ASPECTS OF THE CBR DELIVERY SYSTEM



I. INTRODUCTION TO COMMUNITY-BASED REHABILITATION(CBR)

What is it? What is it not?

CBR aims at strengthening the relationship, and promoting interaction between individuals with disability, their families and the social organization in which they live, namely their community.



The role of rehabilitation services at community level is to strengthen relationships and promote interaction between all three units. To do this, the concept envisages that the community leadership takes the on the responsibility. This is the "base" in CBR.

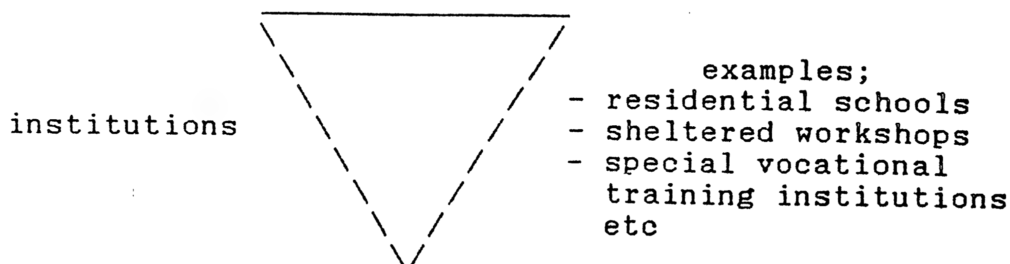
However, communities cannot do this without support. CBR calls for, and encompasses, all services at other levels that are available, and could be made available, to support the community's efforts. Services provided by Institutions are a vital part of the supportive component of CBR.

What is being stressed here attempts to dispel two particular myths on which much current literature on CBR is being written, and to emphasize that community-based rehabilitation

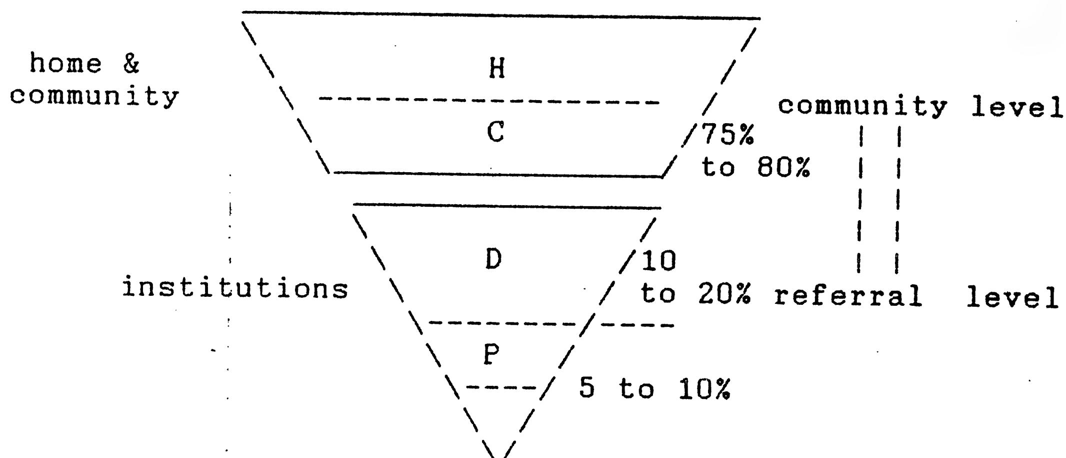
- DOES NOT INVOLVE SERVICES <u>ONLY</u> AT THE HOME AND COMMUNITY LEVEL. IT INVOLVES SERVICES AT ALL LEVELS

- DOES NOT EXCLUDE, NEITHER IS IT COMPLEMENTARY TO, INSTITUTION-BASED REHABILITATION.
  RATHER, IT ENCOMPASSES SERVICES PROVIDED BY INSTITUTIONS AS A VITAL COMPONENT OF ITS SYSTEM.

Up to the present time services for people with disability have been delivered in institutions.



For reasons that will be discussed later, the pattern of service delivery is changing to actively involve people with disability,their families and communities, and to start with community level services.



At community level - home level training
- community level support services
- management

At referral levels i.e.district,province,central
- referral needs arising from the community are met; services are stratified according to demand and frequency of usage, cost and manpower availability.
This requires increasingly specialised manpower and effective management at each higher level.

Through the experience of CBR programmes globally, WHO estmates that;

75 - 80% of needs are met at community level
10 - 20% middle levels
5 - 10% tertiary levels

CBR is a concept, a concensus of ideas; ideas put forward as a foundation for formulating strategies to improve the quality of life of individuals who, because they have some kind of disability, are disadvantaged in Society.

There may be many ways of applying the concept of CBR, but if any is to be called CBR, they should conform to the basic concept. If they do not, then such approaches should be called by other names. For instance, approaches which involve working directly with the family with no responsibility taken by the community leadership should be perhaps called "family-based" or "community-level" rehabilitation etc.

CBR in Summary;

In CBR people with disability and their families and community take primary responsibility for rehabilitation and are supported by services at other levels.

Rehabilitation takes place in the environment of the persons home and community, building on the resources of the community.

It is undertaken by;-

-the individual & the family
-the community
-with the support of referral services

It uses appropriate technology at each level.

The focal point of CBR is the community in which people who have disability and need rehabilitation live.

CBR is being developed to meet comprehensively as one service the needs of those with the most prevalent disabilities in developing countries;-

- o difficulty seeing
- o difficulty hearing
- o dificulty speaking
- o difficulty learning (intellectual disability)
- o loss of sensation(due to leprosy)
- o disability due to fits (epilepsy)
- o difficulty moving
- o show strange behaviour (schizophrenia)
- o combinations of these disabilities

EXPRESSED NEEDS OF PEOPLE WITH DISABILITY

A primary focus of early field trials of CBR was to find out the expressed rehabilitation needs of people with disability, their families and community. (not just the perceived needs of professionals). The needs determined globally are listed in Form No 2 of TDPC (1983)

These are the handicaps that prevent people with disability from fulfiling their role in Society. A rehabilitation service must therefore provide people with disability with suitable interventions to fulfil these needs and overcome these handicaps.

These needs can be summarized into the following areas;

1. early detection and identification
2. promotion and protection of rights
3. socialization within family and community
4. communication
5. schooling
6. independence in activities of daily living
7. independence in mobility, and freedom of access
8. breastfeeding of infants with disability
9. early stimulation for pre-school children
10. income generation/job opportunity/economic production

Therefore the framework of a rehabilitation service must include measures or component services to meet all these needs or handicaps. In addition, to ensure that the service is of maximum benefit to individuals it must include processes for reporting, monitoring, evaluating and reprogramming.

On the basis of this analysis when we look at our existing services for people with disability there are 2 significant outcomes;

(i) we realize the inadequacy of our existing services

(ii) we see the particular need for multisectoral collaboration in rehabilitation.

TOOL FOR IMPLEMENTING CBR

The capacity of people with disability, families and communities to take responsibility for rehabilitation is increased, and their self reliance strengthened, by the possesion of knowledge and skills necessary for rehabilitation.

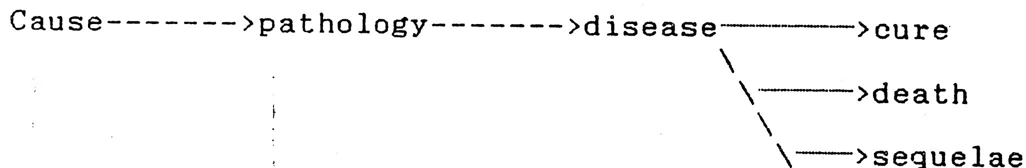
This information is diseminated is through the use of a Manual "Training in the Community for People with Disabilities" prepared by WHO. This Manual is, and should be, adapted by each country after a period of field-testing to suit it´s own socio-cultural ethos.

II BASIC CONCEPTS RELATED TO DISABILITY

Before going further, in order to understand the changes in rehabilitation occurring internationally, it is necessary to discuss some concepts relating to disability.

1. The Disease/Disability Process (ref. WHO TRS 668, 1981)

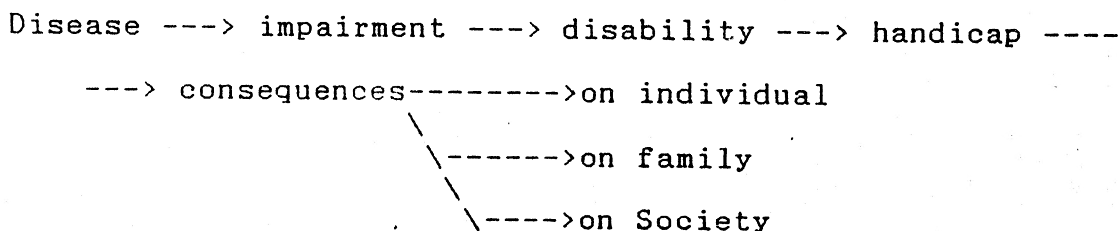
There is a tendency to view illness purely in medical terms, as illustrated in the following model;-



Medical care in developing countries does not give much priority to dealing with the sequelae of disease; it is mostly concerned with the treatment of disease.

The sequelae of disease interferes with the ability of individuals to carry out their daily functions and obligations.

The traditional model of illness therefore needs to be enlarged to take into account the socio-economic effects of illness.
The sequence following disease can be summarized as the following;-



2. Definitions;

<u>Impairment:</u> In the context of health experience, an impairment is any loss or abnormality of psychological, physiological or anatomical structure or function.

<u>Disability:</u> In the context of health experience, a disability is any restriction or lack (resulting from an impairment) of ability to perform an activity in the manner or within the range considered normal for a human being.

Handicap: In the context of health experience, a handicap is a disadvantage for a given individual, resulting from an impairment or disability, that limits or prevents the fulfilment of a role that is normal (depending on sex, age and social and cultural factors) for that individual.

NOTE:
(i) impairments and disabilities may be visible or invisible, temporary or permanent, progressive or regressive.
(ii) a handicapping condition is not always the result of a disability; sometimes impairments cause handicaps without necessarily passing through the intermediate stages of disability.
(iii) besides individual limitations resulting from impairment/disability, social and environmental factors can increase or reduce handicapping conditions.

To take some EXAMPLES to illustrate the disability process;

CAUSE	DISEASE	IMPAIRMENT	DISABILITY	HANDICAP
virus	polio	paralysed muscles	of movement	cannot walk does not play development delayed
malnutrition	mental retardation	low intellect	difficulty in acquiring skills and knowledge	no school no work
hyper-tension	stroke (CVA)	disturbed brain function	loss of movement	unable to do self-care
road traffic accident	amputation	loss of leg	loss of movement	no work
home accident	burns	scarring, deformity	none	does not socialize